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Yale University

Combating the Stigmatization of Leprosy:

How the first decade of *The Star*'s publication made the case for romantic relationships and the preservation of domestic life in the Carville Leprosarium

Gabriela Reed

September of 1941 marked the publication of the inaugural issue of *The Star*, a magazine created by the residents of the Carville Leprosarium in an attempt to combat the widespread stigmatization of leprosy.¹ The journal's establishment by Stanley Stein, a blind leprosy patient, coincided with a marked shift in the country at large. While a great degree of acquiescence to public health measures accompanied the Great Depression, the end of the Depression and the arrival of the 1940s heralded a greater desire to agitate for personal freedoms.² *The Star* effectively combated the stigmatization of leprosy in myriad ways, but perhaps one of its most important campaigns came in addressing the harsh social restrictions in place at the Leprosarium in the realm of romantic relationships and marriage. In the newsletter's first ten years, from 1941 until 1951, *The Star* worked to depict courtship, marriage, and domestic life as natural and beneficial parts of life worthy of being celebrated irrespective of whether a person had leprosy. By these means, the publication aimed to cast aside overly restrictive regulations and to fully integrate and accept married couples into leprosarium life.

The Star as it existed in the 1940s was not entirely a fresh start as a publication, but rather the follow-up to *The Sixty-six Star*, which Stein began in 1931 only to see it come to an end three years later. When *The Star* reappeared in 1941, it did so with a much more clearly articulated mission: "Radiating the Light of Truth on Hansen's Disease." Stein believed that education provided the clearest path to achieving equality for leprous people; to this end, his revival of *The Star* set its broad objective as dispelling misinformation about the disease and thereby changing

¹ Though the disease at hand is known by both "leprosy" and "Hansen's disease," this paper will use the term "leprosy" throughout. As the paper is addressing the stigmatization of the disease, it seems more appropriate to engage with the more stigmatized term.

² Fairchild, Amy. "Leprosy, domesticity, and patient protest: the social context of a patients' rights movement in mid-century America," *Journal of Social History* 39 (2006): 1017.

the public's conception of leprosy. One of the magazine's key initiatives was to replace the word "leprosy" with the less derogatory term "Hansen's disease."³

Residents of the National Leprosarium felt profoundly the stigmatization of leprosy and their attempts to fight it were widespread in scope, but united by the emphasis they placed on both personal rights and public education. The ethos of individual liberties stemmed in part from President Franklin Roosevelt's praising of the four freedoms, expressed in his January 1941 address to Congress: freedom of speech, freedom to worship, freedom from want, and freedom from fear. The former two, in particular, resonated with patients with leprosy who desired greater freedom within Carville. Additionally, in the 1940s, experimentation with a class of drugs called sulfones (namely Promin and Diasone) yielded unprecedented success in the treatment of leprosy. Patients praised the new therapy as clearing the path to not merely living, but also specifically what they called "'Master of My Fate Living'".⁴ Such an interpretation further demonstrates the growing focus on personal autonomy at this time.

With the arrival in the 1940s of a cure for leprosy, the promise of eventually leaving the Leprosarium became a distinct possibility for patients. Despite this advance, patients maintained the mental conception of the Carville Leprosarium as a lifelong sentence. Louis Boudreaux, who edited *The Star* after Stein's death in 1968, spoke of the overwhelming sentiment in the 1940s: "In those days, when we came here, we were here for life, most of us. And—most people who left here in those days went through the hole in the fence, and not the gate."⁵ If the Leprosarium were to be a home until death, then it must necessarily allow patients to experience all those

³ Heather Varughese John, "Translating Leprosy: The Expert and the Public in Stanley Stein's Anti-stigmatization Campaigns, 1931-60," *Journal of the History of Medicine and Allied Sciences* (2012).

⁴ Amy Fairchild, "Leprosy, domesticity, and patient protest," *Journal of Social History* 39 (2006): 1017.

⁵ Marcia Gaudet and James Carville, *Carville: Remembering Leprosy in America* (Jackson, MS: University Press of Mississippi, 2004), 64.

milestones that highlighted life outside Carville, dating and marriage being among the most significant. Indeed, Boudreaux brings up the “hole in the fence,” the phrase that patients used to refer to sneaking out; one of the most common rationales for running away was to be married, as such was prohibited on Carville grounds.

The institution of marriage specifically, and romantic relationships more generally, provide an ideal case study through which to examine the broader social impact of the stigmatization of leprosy. Marriage functions as a logical step in a fulfilling relationship, even more so during the 1940s than today; the bond of marriage asserts an essentially permanent commitment to another, both publicly and privately. Broadly speaking, society’s perception of leprosy will influence people’s marriage decisions and the way that children of leprous individuals are treated. Marriage can thus serve as a sort of litmus test of the status of current leprosy stigmatization; if people with leprosy are viewed as outcasts or inferiors, their rates of marriage are likely to be lower. The causes of this effect are varied. Perhaps, as was the case in Carville, marriage between infected people is restricted by authorities who fear it would propagate the transmission of disease or who are enforcing the idea of the diseased as lesser people. It is also possible that those without leprosy would refuse to marry leprous people, again a result of the sort of superiority complex of the healthy partner. One oft-neglected aspect of the stigma of leprosy is how it leads not only to low self-esteem, but to accompanying destructive behavior, such as alcohol or drug abuse; this, in turn, can lead to the disintegration of an otherwise happy marriage.⁶

Though the Carville Leprosarium did not explicitly ban marriage, the institution’s regulations were clearly designed to prohibit the advancement of any sort of heterosexual

⁶ Tom Frist, *Don’t treat me like I have leprosy*, International Federation of Anti-Leprosy Associations (ILEP), 2003.

romantic relationship. When *The Star* was launched, the informal rule was that married couples could not live together unless they were able to acquire one of the cottages on the hospital grounds; it was, however, rare that patients had the monetary or other resources to do this.⁷ A couple of years later, in April 1943, Dr. Guy Henry Faget, the Medical Officer in Charge (MOC) at Carville, published a list of eleven detailed rules and regulations under the headline, “What the Patient Should Know about Hansen’s Disease.” Of these, one in particular aroused the protests of patients. Though nestled in the document as item 6b, apparently not even warranting its own enumeration, the implications of the following are weighty: “Patients shall on no account visit the quarters of patients of the opposite sex without permission of the medical officer in charge. Visiting between patients of the opposite sex shall be permitted in the appointed visiting place only at such hours as may be set aside for that purpose.”⁸

Though Faget’s piece encompassed many realms of life, such as clinical examinations and discharge, it was the regulations applying to social life that attracted the most attention. Patients were particularly riled by rules that limited their interactions with the opposite sex and which mandated isolation within “the reservation,” as Carville was euphemistically called.⁹ The publication of these rules catalyzed a conflict, explicitly played out in the pages of *The Star*, between those in favor of more rights for patients and those who believed patients’ rights should be conceded for the general good of the community. The latter group believed that more intimate contact between patients would aid the transmission of leprosy, and that efforts to prevent the disease’s spread thereby demanded an end to marriage and the dating interactions preceding it.

The Star occupied a unique role in the controversy because, as the primary means of

⁷ Amy Fairchild, “Community and Confinement: The Evolving Experience of Isolation for Leprosy in Carville, Louisiana,” *Public Health Reports*, May-June 2004: 365.

⁸ Guy Henry Faget, “What the patient should know about Hansen’s disease,” *The Star* April 1943: 2-3.

⁹ Amy Fairchild, “Community and Confinement,” *Public Health Reports*, May-June 2004: 365.

communication throughout the National Leprosarium, it was responsible for airing both sides of the argument. Still, an inequality of numbers was all too evident—one side was represented only by Faget and the other, less visible, members of the administration, while the other had the entire cohort of patients in its favor.

For most women at the Carville Leprosarium, regulations that infringed on their right to something that resembled normal dating were part of a greater violation of these women's domestic dreams. A prominent example can be seen in the connection between the regulation surrounding food and that of opposite-sex visitation. At Carville, the evening meal was served at 4:00 p.m., an hour that felt particularly early in light of the recent trend to eat dinner at increasingly later times. Though the difference may seem relatively innocuous, it actually carried significant weight, creating as it did the need for a meal later in the day. This need was filled by women who, in the closest thing to formal dates that existed within Carville, cooked meals in their own dormitories and then shared in these meals with their boyfriends. The collusion of food and romance in Carville held deep significance and an affront on one could easily translate into an attack on the other. The dynamic between the two was not to be underestimated, especially given each of their individual significances; as Amy Fairchild wrote, "So, if food was one of the preoccupations at Carville, sex was the other."¹⁰

The Star captured the ideal of domesticity in its pages, too. Notably, a poem entitled "Yearning," first published in the magazine in 1945, highlighted the desire for normal home life with the case of a particularly high profile patient, Betty Martin. Betty had met her husband, Harry, at Carville and the two had escaped through the infamous "hole in the fence" to be married; however, as their sickness worsened, they were forced to return to Carville for

¹⁰ Amy Fairchild, "Leprosy, domesticity, and patient protest," *Journal of Social History* 39 (2006): 1018-19.

treatment. Back at the Leprosarium, Betty's hope for something of a normal life persisted. She wrote of a desire for "The blessing of my little home; A place I'll call my very own."¹¹ The phrase "little home," which was repeated numerous times in the short 12-line poem, certainly drew attention to patients' persistent wish to escape the pervasive institutionalization of Carville and find solace and comfort in home life.

Another approach to arguing in favor of allowing marriage for people with leprosy came from a cross-cultural perspective. A May 1945 article in *The Star* examined a leprosarium in Panama and reveled in the discovery that, "...by the efforts of Dr. Hurwitz [the director] and his wife to keep things as normal as possible the people were more happy than I had anticipated and so interested in the affairs of the world." In the following sentence, as if to give the explanation for such happiness, the article discusses how the leprosarium permits marriage and even provides special housing for married couples. The case for marriage was furthered by the article's clarification—offered by an authoritative doctor—that leprosy is not inherited, and that mothers with leprosy can therefore give birth to perfectly healthy babies.¹²

One of the most notable campaigns launched by *The Star* in the 1940s concerned the contraction of leprosy by Gertrude Hornbostel, the wife of Major Hans Hornbostel, a war hero in the Philippines.¹³ In an unprecedented request, Hans asked to accompany his wife to Carville, despite his own lack of illness; surprisingly, his request was granted. The event garnered national media attention, which was overwhelmingly, and perhaps unsurprisingly, negative. Headlines included the San Francisco *Call Bulletin*'s "San Francisco Wife Leper: Army Mate Begs to

¹¹ Betty Martin, "Yearning," *The Star* September 1945: 2.

¹² Harold Chalfant, "This Is Palo Seco," *The Star* May 1945: 1.

¹³ Michael Mizell-Nelson, "Treated as Lepers: The Patient-Led Reform Movement at the National Leprosarium, 1931-1946," *Louisiana History: The Journal of the Louisiana Historical Association*, Vol. 44, No. 3 (Summer, 2003): 323.

Share Isolation for Life”¹⁴ and “Man Asks to Go to Leper Wife” in the *Sarasota Herald-Tribune*.¹⁵ But *The Star* capitalized on the hype surrounding the incident, seizing the opportunity to dispel much of the false information circulating about leprosy and its spread.

Indeed, Gertrude and Hans made the transition to Carville relatively smoothly, as Gertrude expressed in a 1947 piece in *The Star*. She wrote, “We were able to buy a tiny cottage on the hospital grounds [...] and both my husband and I are now able to have some home life.”¹⁶ The Hornbostels also made a great step in the march toward full destigmatization of leprosy when they became the first to keep their true names while at Carville, a decision that Gertrude discussed passionately and at length in a February 1949 article in *The Star*. She bemoaned that more leprosy patients were not comfortable enough to maintain their identities, writing that, “The constant fear of having his identity revealed prevents him from recuperating as fast as he would if he did not have that worry.”¹⁷ The Hornbostels’ public “coming out,” as it were, done with their love so clearly intact despite—and perhaps strengthened by—leprosy, made the couple a perfect example of how happy and healthy relationships could flourish even when one or both partners were leprosy.

The intense focus on achieving integration and equality for the married couple with leprosy, including the aim to allow leprosy couples to lead a satisfying domestic life, did not preclude the inclusion of single adults in this effort. By avoiding the alienation of the many unattached men and women, the movement became much stronger than it would otherwise have been, simply because of the number of people behind it. Part of this may be attributed to the relationship status of Stein, the engineer and the primary man behind *The Star*. Stein was an

¹⁴ Tony Gould, *Leprosy in Modern Times* (London: Bloomsbury, 2005), 256.

¹⁵ “Man Asks to Go to Leper Wife,” *Sarasota Herald-Tribune* May 16, 1946: 4.

¹⁶ Gertrude Hornbostel, “As I See It—After One Year,” *The Star* November 1947: 5.

¹⁷ Gertrude Hornbostel, “The Truth Shall Make You Free,” *The Star* February 1949: 3-4.

unabashed and unapologetic bachelor, yet simultaneously the primary voice behind the campaign to grant married couples housing within the Carville Leprosarium.¹⁸ Perhaps his commitment to the mission stemmed from his sympathy for those struggling with finding romance, expressed in Stein's autobiography, *Alone No Longer*. During his first days at Carville, Stein reminisced about the amorous prospects he had left behind when he came to the Leprosarium. "I couldn't quite shut out the image of one girl in particular [...] a girl whom I sincerely loved yet dare not ask to marry because of the frightful secret I could not share with her."¹⁹ Stein's ability to fully empathize with the married, yet maintain his place among the single, exemplified the inclusive nature of the marriage rights campaign that he led; rather than marriage rights, Stein expanded the movement to be seen as one for social rights.

The Star's work to combat the stigma of leprosy through promoting the advancement of romantic relations amongst patients was also accomplished via more implicit means. Simply by integrating frequent mention of happily married husbands and wives into the publication's pages, *The Star* could transform marriage from a surprising topic in the context of leprous patients, to an expected item of conversation. And as shown by the mission to eliminate "leprosy" in favor of "Hansen's disease," Stein was clearly aware of how the use of language could shape reality. By this principle, the corollary to making marriage in Carville a more common subject in *The Star* would be making marriage in the real world of Carville more commonplace. To this end, many of the routine columns in *The Star* centered on domestic themes. Ann Page's segment

¹⁸ Amy Fairchild, "Leprosy, domesticity, and patient protest," *Journal of Social History* 39 (2006): 1018.

¹⁹ Stanley Stein, *Alone No Longer: The Story of a Man Who Refused to Be One of the Living Dead* (New York: Funk and Wagnalls Company, 1963), 10.

entitled *The Ladies*, for example, was a mainstay; this segment was a formal place to address gossip of Carville, which frequently revolved around recent or impending marriages.²⁰

Amy Fairchild writes that, when *The Star* reemerged in 1941, it quickly became patients' primary mode of voicing their concerns and complaints, and organizing to effect change within Carville.²¹ Patients were keenly aware of the extent to which they were denied so many of the basic rights of people without leprosy, living outside the confines of the National Leprosarium, and they felt strongly that this was unjust. Further bolstered by the discovery of antibiotic therapy in the form of sulfones, which turned the long-awaited cure for leprosy into reality, those with leprosy saw no reason that they should be treated as "less than" in any sense—particularly not when it came to the intimate relationships they fostered with others, whether those others shared in their diagnosis or not. President Roosevelt's four freedoms resonated with the patients of the Leprosarium, and they rallied behind their right to engage in all those things that at the time defined "normalcy" in terms of romantic relationships—dating, marriage, and eventually settling into the comfort of domestic life.

Upon arriving at Carville, Betty Martin lamented that, "...friends, love, normal living were waiting for [her] at home."²² In its first ten years, *The Star* aimed to bring these same things—these basic human rights—to the patients of the Carville Leprosarium. Through the magazine's coverage of current events and its focus on overturning the rules that made dating impossible and forbid patient marriages, allowances for romance were gradually reintegrated into the lives of those with leprosy. As leprous patients' social lives more and more resembled those of the men and women outside Carville, the burdensome stigma of those with leprosy was diminished, and Martin's exalted ideal of "normal living" became increasingly closer to reality.

²⁰ *The Star*, 1941-1951, Volumes 1-10.

²¹ Amy Fairchild, "Community and Confinement," *Public Health Reports*, May-June 2004: 365.

²² Amy Fairchild, "Community and Confinement," *Public Health Reports*, May-June 2004: 366.

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